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Secretary Shinseki Receives Udall Award for Support of Veterans with Parkinson's and Commitment to Public Service



Parkinson's Action Network is thrilled to be honoring Secretary Eric K. Shinseki with the Morris K. Udall Award for Public Service for his tireless efforts advocating for Veterans health issues and recognizing Parkinson's disease among the illnesses that affect thousands of our

brave men and women.

In 2010, under Secretary Shinseki's leadership, the U.S. Department of Veterans Affairs (VA) recognized Parkinson's disease on the list of illnesses associated with exposure to the herbicide known as Agent Orange. Using evidence from a July 2009 National Academy of Science's Institute of Medicine report, Veterans and Agent Orange, this decision simplified and accelerated the benefits application process for Vietnam veterans with Parkinson's disease.

Secretary Shinseki has also been a supporter of the VA's [Parkinson's Disease Research, Education and Clinical Centers](#), which treat Veterans with various movement disorders in addition to Parkinson's disease, such as essential tremor,

restless leg syndrome, dystonia, atypical parkinsonian disorders, or "parkinson plus" syndromes. There are currently about 80,000 veterans affected by Parkinson's disease and the VA centers provide them with critical patient care in several cities around the country. We, along with the rest of the Parkinson's community, appreciate the attention and funding given to these centers and the people they serve.

Most recently, the VA issued a proposed rule to make it easier for Veterans to receive health care and compensation for certain illnesses, including parkinsonism, dementia, and depression, which have been linked to moderate to severe traumatic brain injury. This is an example of how the VA, under the Secretary's leadership, ensures that its benefits programs keep up with the latest science.

Prior to his time at the VA, Secretary Shinseki served as the chief of staff in the U.S. Army. During his long military career, he also received two Purple Hearts for injuries in Vietnam. Because of his injuries, including losing part of his foot, Shinseki knows first-hand the challenges of a disabled Veteran.

His list of accomplishments should make it clear why he will be honored with the Morris K. Udall Award for Public Service at this year's Morris K. Udall Awards Dinner.

Udall Award (continued from front page)

The public service award is named for Morris “Mo” K. Udall, who served in the U.S. House of Representatives for 30 years and was a candidate for the Democratic Presidential nomination in 1976. During Udall’s distinguished career, he infused American politics with his singular style of humor, grace, and dignity. Many of today’s leaders – both Democrats and Republicans – have cited Udall as an inspiration and role model. As a partisan Democrat, he was a much-feared debate opponent, but he was fair and always decent. It is this spirit that the Morris K. Udall Award for Public Service is presented to Secretary Shinseki, who has made important contributions to public policy with humor, grace, and dignity.

Alan Oates, director of legislative affairs, research and special projects at the U.S. Military Veterans with Parkinson's (USMVP), had the following to say about Secretary Shinseki.

"Veterans respect him for his military service and for standing his ground. After his decision to add Parkinson's and two other diseases as service related for exposure to Agent Orange, General Shinseki met with members of our group. In response to our thanks, he replied, 'It was the only decision I could make, it was the right decision.' General Shinseki is a courageous leader who has earned the respect of those he serves. He is my kind of soldier."

Shinseki is the first Asian-American four-star general in U.S. history. He was born in Hawaii to Japanese-American parents and is married with two children. (article retrieved from www.parkinsonsaction.org/news)

New PADRECC Research Publication Secondary Data Analysis of PADRECC CSP Study Submitted by Daniel Weintraub, MD, Philadelphia PADRECC

Be on the lookout for a newly published article using a secondary data analysis of the PADRECC’s CSP Study, entitled *Suicide Ideation and Behaviors after STN and GPi DBS Surgery for Parkinson's Disease: Results from a Randomized, Controlled Trial*. Drs. Weintraub, Duda, Luo, Sagher, Stern, Follett, Reda, Weaver and Ms. Carlson will soon have an article in the Journal of Neurology, Neurosurgery & Psychiatry (JNNP).

The research team looked at the risk of suicide behaviors post-deep brain stimulation (DBS) surgery in Parkinson's disease (PD). They assessed if suicide ideation and behaviors were more common in PD patients randomized to DBS surgery versus best medical therapy (BMT); and for those randomized to subthalamic nucleus (STN) versus globus pallidus interna (GPi) DBS surgery.

In Phase 1 of the Veterans Affairs CSP 468 study, 255 PD patients were randomized to DBS surgery (n=121) or 6 months of BMT (n=134). For Phase 2, a total of 299 patients were randomized to STN (n=147) or GPi (n=152) DBS surgery. Patients were assessed serially with the Unified Parkinson’s Disease Rating Scale Part I depression item, which queries for suicide ideation; additionally, both suicide behavior adverse event data and proxy symptoms of increased suicide risk from the Parkinson’s Disease Questionnaire (PDQ-39) and the Short Form Health Survey (SF-36) were collected.

Study outcomes for Phase I reported no suicide behaviors and rare new-onset suicide ideation (1.9% for DBS vs. 0.9% for BMT; Fisher’s exact p=0.61). Rates of suicide ideation at 6 months were similar for patients randomized to STN vs. GPi DBS (1.5% vs. 0.7%; Fisher’s exact p=0.61), but several proxy symptoms were worse in the STN group. The investigators concluded that DBS surgery study in PD patients did not support a direct association between DBS surgery and an increased risk for suicide ideation and behaviors.

What is Expiratory Muscle Strength Training (EMST)?

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The EMST technique. Over a decade of work from our laboratory describes the use of a technique called expiratory muscle strength training or EMST. EMST is enabled by the use of a portable, handheld device, known as a pressure threshold device. EMST improves maximum expiratory pressure (MEP), cough effectiveness, and swallowing function in case series, single group and randomized clinical trials (see Troche et al., 2010¹ for a complete list of references which include our previous work as well as Sapienza et al., 2011²). EMST is simply a behavioral treatment option. It is a tool for rehabilitation specialists to assist with improving certain skeletal muscles' ability to increase force by exposing them to a load or a "weight" (See Figure 1).

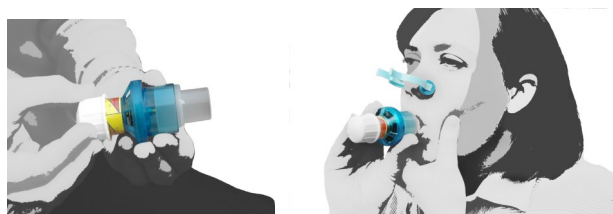


Figure 1. Photographs of expiratory muscle strength and placement in mouth.

Drs. McConnell and Romer contributed an article called "Respiratory muscle strength training (RMST) in healthy humans: resolving the controversy".³ In this article the rationale for specific respiratory muscle training which includes EMST and inspiratory muscle strength training or IMST, were reviewed. There are several techniques used to accomplish RMST, such as resistive loading and pressure threshold loading. The conclusions from this literature were inspiring as it supported RMST as a treatment for respiratory muscle fatigue and improved exercise performance. With the use of the appropriate methodologies and trial design, as well as selection of valid and sensitive outcome measures, RMST has been transferred to patient populations including those with Parkinson's disease, COPD, spinal cord injury, multiple sclerosis, sedentary elderly, and to others.^{1,2,4-8}

Our research group at the University of Florida has specifically focused on the EMST technique for its effects on breathing with new applications of it to functions such as swallowing and cough.^{1,8,9} Additionally, EMST has been incorporated as preventative exercise for elderly¹⁰ and as a mechanism for strengthening expiratory muscles for song and wind instrument performance (e.g. Sapienza, Davenport & Martin).²

Motor exercise protocols like EMST, include intensity and/or duration regimens. This means that a clinician or user is prescribing the treatment duration. The variation of the intensity and duration are not random choices. They are based on knowledge adapted from exercise physiology literature, indicating the importance of the amount of exercise performed over time as it relates to both muscular, or myogenic, changes, and changes occurring within the nervous system. Thus, these treatments are often delivered over a time period ranging from 4 – 8 weeks, between 3 - 5 days per week, and 1 – 3 sessions per day. Within a daily session, 25 – 30 repetitions are typically completed.^{11,12}

The EMST treatment protocol we have incorporated clinically as well as within our research design incorporates intensity levels targeting muscle strength and thus targeted muscle groups may benefit from improved force-generating capability. It is the improved force generating capacity which lends itself to hypotheses regarding changes to function. Use of the EMST technique for affecting swallow function relies on cross training of the submental musculature as discussed by Wheeler et al (2008).¹³ EMST effects on swallow function are covered in detail in Pitts et al.⁹; Troche, et al.⁴; Wheeler et al.¹³ The Troche et al.⁴ work is the most comprehensive work to date on Parkinson's disease detailing the outcomes of a randomized clinical trial and its positive effects of swal-

Expiratory Muscle Strength Training (continued from page 3)

of a randomized clinical trial and its positive effects of swallow timing, swallow movements and airway protection.

Common to all potential strength training treatments is the fact that treatment must be sustained over time in order to result in physiologic or functional gains with regard to these improved functions. Based on study findings of EMST specifically, it can be hypothesized that no less than 2 weeks of treatment, delivered 3-5 times per week can be recommended with reasonable expectation for improvements. Development of a maintenance program will be necessary to prevent detraining effects common to the cessation of strength training protocols.¹⁴⁻¹⁶

Why use it for persons with Parkinson's disease?

Many individuals with Parkinson's disease (PD) suffer from obstructive or restrictive pulmonary disease.¹⁷⁻²⁰ This phenomenon is thought to be influenced by reduced respiratory muscle strength and by increased chest wall rigidity.¹⁸ Given that persons with PD often succumb to pulmonary sequelae and pulmonary dysfunction has been identified at all stages of disease. Based on that, management of pulmonary compromise is a top priority throughout the course of the disease.^{18,21-32} There is mounting evidence suggesting that EMST improves ventilatory function in persons with neurodegenerative disease (e.g. Chiara, et al.⁴, Kim, et al.¹⁰). As skeletal muscles, the respiratory muscles seem to respond well to strength training.^{4,7,10,33,34} EMST improves respiratory muscle pumping force capacity which is important in ventilation. In fact, pilot testing revealed a 158% improvement in MEP with EMST training in PD,^{35,36} suggesting that EMST is a viable treatment option targeting expiratory muscles and could also result in improvement in pulmonary function – a function that is intricately related to ventilation of the lung.

What is the EMST device?

The EMST150™ device (Aspire Products, LLC) is a hand held device that provides a consistent pressure load on expiration. The training results by simply blowing into the trainer to overcome the threshold load which is easily adjusted by a calibrated spring inside of the device. The pressure threshold maximum is 150 cmH₂O (Figure 1). Users of the device can hear and feel the release of the spring loaded valve once the threshold load set on the device is met or exceeded during the expiratory phase of breath.

Common Training Protocol

Place a nose clip provided on your nose to prevent air loss through the nose during high effort blowing

- Turn the knob on the pressure threshold EMST150 device until the small metal screw on the bottom lines up with the number 30.
- Take a deep breath in; insert the EMST150 mouthpiece in your mouth, behind the teeth, making a tight lip seal around the mouthpiece.
- Don't breathe any air out until the mouthpiece is securely in place. Use the hand that is not holding the device to help secure the lips around the mouthpiece, if needed.
- Next, blow hard and fast through the device until air rushes through, and then stop.
- If able to accomplish Steps 1-4 easily, turn the knob clockwise ¼ turn and repeat. If unable to move air through the device, turn the knob ¼ turn counterclockwise and continue to do that until able to move air through the device.

****Continue turning the knob clockwise until you are unable to move air through the device easily. This stopping point will be the MAXIMUM pressure you are able to create. The best analogy that we have used to help patients understand the concept of strength training is that of the pin in the weight machine at the gym. Place the pin in the machine; find the weight that makes force generation difficult but not so difficult that overstraining occurs.**

Ease of Training

EMST training can be done in the home or with the aid of rehabilitation specialist. It represents a short-term treatment that can be quantified and translated into functional outcomes that may directly improve functions related to breathing, cough and swallow. The impact is high because of its high cost-effectiveness, ability to minimize direct therapist time required to rehabilitate the deficits, reduced need for clinical resources and patient travel time and because it can be developed into a home-based therapy program.

Expiratory Muscle Strength Training (continued from page 4)

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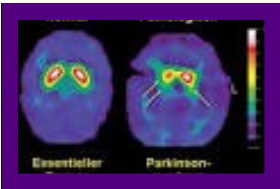
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A Brief Overview of DaTscan

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Although radiotracers that target presynaptic dopamine transporters have been used on a research basis for many years, (¹²³I) Ioflupane single-photon (emission tomography, (DaTscan SPECT, GE) was the first to be approved by the FDA as a tool to assist in the evaluation of adult patients with suspected Parkinsonian syndromes, and to distinguish these syndromes from essential tremor¹. In Parkinson's disease, loss of nigrostriatal dopaminergic projections results in reduced uptake of radiotracer in the striatum, especially the posterior putamen contralateral to the clinically most affected limbs. Since some free¹²³I may be present in the injected radiopharmaceutical, patients who undergo DaTscan should have "thyroid blockade" prior to the procedure with potassium iodide oral solution (SSKI) drops. Medications such as stimulants, bupropion,



and benzotropine, which have high affinity for dopamine transporters, should be held for at least five plasma half-lives prior to DaT scanning; other medications with small effects on DaT uptake can probably be continued

(Table 1).^{2,3} In each case, the desire to optimize scan quality

should be weighed against the risks of holding therapeutic medications.

Since Parkinson's disease is a clinical diagnosis, for which the best premorbid gold standard is longitudinal follow-up, the question of when DaTscan is useful in clinical practice arises. A recent analysis of the studies performed to obtain FDA approval suggested that the clinical examination has equivalent sensitivity and specificity to a DaTscan.⁴ However, other investigators have contended that information from the scan does alter diagnostic confidence and streamline treatment decisions.⁵

For a biomarker such as DaTscan to improve clinical management it must extend diagnostic accuracy, predict disease onset or rate of progression, or track treatment-based changes in long-term outcome. Studies that have investigated the relationship of dopamine transporter imaging to delayed (6-48 months) clinical diagnoses have suggested that dopamine transporter imaging has approximately 80% sensitivity and greater than 90% specificity for a longitudinal clinical diagnosis of Parkinsonism.⁶ Relatively small neuropathological studies have suggested sensitivity and specificity of 85

Table 1
Common Pharmacologic Agents Known to Affect DaT Uptake

Significant effect (>20%)	Recommended discontinuation (days)
Cocaine	2
Fentanyl (IV)	1
Methylphenidate	1-2
Methylamphetamine	2
Modafinil	3
Amphetamine, Dexamphetamine	7
Benzatropine	5
Bupropion	8
Minor effect (<15%)	Optional discontinuation (days)
Venlafaxine, duloxetine	3
Fluvoxamine, Paroxetine, Memantine	5
Amantadine, imipramine, ephedrine, sertraline	6
Citalopram, Escitalopram	8
Clomipramine	21
Pimozide	28
Fluoxetine	45
Levodopa	little effect
Selegiline	little effect
Pramipexole	little effect

Table 1 was adapted from:
Kagi G, Bhatia KP, Tolosa E. The role of DAT-SPECT in movement disorders. *J Neurol Neurosurg Psychiatry* 2010;81:5-12.
and
Cummings JL, Henchcliffe C, Schaier S, Simuni T, Waxman A, Kemp P. The role of dopaminergic imaging in patients with symptoms of dopaminergic system neurodegeneration. *Brain* 2011;134:3146-66.

DaTscan (continued from page 6)

and 86%, respectively, for pathologically confirmed Parkinsonism (DaTscan briefing document for Peripheral and Central Nervous System Advisory Committee Meeting Aug 11, 2009; available at www.fda.gov). This means that one can be fairly certain that a person with an abnormal DaTscan has Parkinsonism. However, the negative predictive value is less certain. In several clinical trials, 15-21% of subjects with clinical symptoms of Parkinson's disease had normal positron emission tomography or SPECT with dopamine synthesis or transporter radiotracers. Longitudinal follow-up of patients and "scans without evidence of dopaminergic deficit" (SWEDDs) has shown striatal radiotracer uptake to remain relatively stable over time (in contrast to the expected 6-13% annual decline expected in Parkinson's disease).^{7,8} Some SWEDD patients were later diagnosed with dystonic tremor.

From a clinical point of view, another situation in which DaTscan can be useful is in the distinction of medication-induced from neurodegenerative Parkinsonism. Many patients treated with neuroleptic medications have motor signs of Parkinsonism; however, these patients are frequently psychiatrically fragile such that trials of medication withdrawal may result in hospitalization. Some studies have indicated dopamine transporter imaging to be normal in 90% of cases of medication-induced Parkinsonism, while other studies are less definitive.⁹ Cases of neuroleptic-induced Parkinsonism with abnormal DaTscans may represent "subclinical" Parkinson's disease that was unmasked by use of the neuroleptic. Other potential uses of DaTscan include distinguishing Lewy body dementia from other forms of dementia such as Alzheimer's disease, and distinguishing essential tremor from tremor-predominant Parkinson's disease. Medication trials are not infallible in distinguishing these disorders, since

Table 2. *Clinical Indications for the Use of Dopaminergic Functional Imaging*

Dopaminergic functional imaging has been shown to be a useful adjunct to the clinical diagnosis of movement disorders in some settings. In general, the risk of functional imaging is justified when the outcome of the examination will help to dictate clinical management. Accurate diagnosis can prevent exposure to inefficacious treatments, improve prognostic abilities and improve cost efficiency. Dopaminergic functional imaging has not been shown to be helpful in differentiating between different Parkinsonian syndromes (e.g. Parkinson's disease, progressive supranuclear palsy, multiple system atrophy, corticobasal degeneration). Decisions on whether or not to conduct scans for a given clinical scenario should also be guided by relevant sensitivity and specificity data as well as the recognition that there is some inter-rater variability in the interpretation of scans. Scenarios in which the result of dopaminergic functional imaging may prove helpful in determining therapeutic interventions include:

- Patients with tremor that is not clearly differentiated into either essential tremor or Parkinsonian tremor.
- Patients with tremor or other features of Parkinsonism in the context of treatment with dopamine-blocking medications known to induce Parkinsonism to determine if the Parkinsonism is likely to be purely drug-induced or if there is an underlying neurodegenerative condition.
- Patients with possible psychogenic Parkinsonism.
- Patients with tremor of unclear etiology that is not responsive to dopaminergic replacement therapies and

both Parkinsonian tremor and essential tremor may be refractory to "correct" therapy. In idiopathic Parkinson's disease, relative preservation of radiotracer uptake in the caudate nucleus compared with putamen, and asymmetry of tracer uptake between hemispheres, may differentiate Parkinson's disease from other Parkinsonian syndromes; however, DaTscan is not approved for this use. Factors that reduce the attractiveness of DaTscan as a diagnostic tool include potential variability in interpretation between centers, possible lower sensitivity in early and preclinical disease stages, and cost. However, used selectively, this test offers a new diagnostic tool that can guide patient management. With these considerations in mind, PADRECC Leadership developed Clinical Guidelines for use of dopaminergic imaging (See Table 2) that will certainly be refined as we move forward.

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Primary Dystonia Misinterpreted as Parkinson Disease: A Case Presentation and Practical Clues

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Introduction

*Dystonia is a movement disorder characterized by sustained muscle contractions frequently causing twisting repetitive movements and abnormal postures.*¹ It can present at any age with a variety of clinical features that may overlap with other movement disorders, making the diagnosis challenging. Patients with dystonia are commonly misdiagnosed.² Dystonic tremor is a significant source of erroneous diagnoses of Parkinson disease (PD) and Essential Tremor (ET).^{2,4} We report an illustrative case of a *patient with DYT1 dystonia that was originally misdiagnosed as PD.*

Case History

A 46-year-old veteran with a five-year history of tremor and a diagnosis of PD was referred to the movement disorders clinic. His initial symptom was left (dominant) hand tremor at rest and with action, followed by head tremor. He had no family history of any movement disorder. Brain MRI was normal. Treatment with trihexyphenidyl, propranolol, and primidone was not helpful. Pramipexole and later, ropinirole, resulted in suboptimal symptom control and excessive sedation. Carbidopa/levodopa provided some improvement. Examination showed slight rotation of his head to the left and tilt to the right, slight hypertrophy of the right sternocleidomastoid muscle, and irregular head tremor that changed direction, frequency and amplitude with changing of head position. Holding his chin with his hand temporarily decreased the tremor. He had a slight intermittent resting tremor of his left thumb, a low amplitude fast tremor of his outstretched arms that worsened with hand inversion and fine movements, handwriting induced dystonic posturing with left arm extension, elbow elevation, wrist hyperextension, and an irregular tremor. The patient reported that he had this “writer’s cramp” since age 18. No rigidity, bradykinesia, nor postural instability was noted. Search for the etiology of his dystonia revealed a GAG946 deletion the *DYT1* gene. Botulinum toxin injections in the cervical muscles, along with carbidopa/levodopa and propranolol, improved the tremor control but the patient remained relatively

disabled. Deep Brain Stimulation (DBS) surgery was thus performed, resulting in complete resolution of his head tremor, and improvement of his hand tremor and posturing.

Discussion

Several features of this patient’s dystonia led to the initial misdiagnosis. First, *parkinsonian tremor is a true resting tremor seen when the extremity is completely supported against gravity.*⁵ In contrast, the hand tremor in our patient was position specific, worse with handwriting, and satisfied criteria of dystonic tremor, which is *focal tremor in the body part affected by dystonia, postural and kinetic; irregular amplitude and variable frequencies, not seen during complete rest, frequently reduced by “gestes antagonists” (sensory cues).*⁵ Presence of head tremor argues against the diagnosis of PD and raises a consideration of ET or dystonia.⁴ His head tremor was typical for dystonic tremor: increasing amplitude and frequency in certain directions, *sensory cue* (touching chin temporarily decreased tremor), and partial *null point* (certain position almost or completely resolved tremor).^{6,7} This patient had minimal dystonic posturing in his neck, but had a disabling head tremor.⁴ Such disproportion between subtle posturing and severe tremor in the same part of the body is not unusual in dystonia,³ especially in the cervical region where the tremor can be the predominant feature.

Second, his left hand dystonia was task specific and not initially noted. The patient himself did not recognize the relationship between his long standing “writer’s cramp” and the head tremor, and his first neurologist did not observe it. As a result, the onset of his symptoms was considered to be at age 39, not 18 when the “writer’s cramp” started. This emphasizes the importance of observing handwriting in patients with dystonia and atypical tremor. *DYT1* dystonia usually manifests before the third decade,⁸ and *genetic testing is indicated if the onset of symptoms is before the age 26 or the patient with late onset has an affected relative with early onset dystonia.*^{6,9} After the actual age of onset was determined in our patient it became evident that he met criteria for *DYT1* testing.

Dystonia (continued from page 8)

Third, as seen in some types of dystonia, our patient had a positive response to levodopa.¹⁰ The mutant *DYT1* gene encodes an ATP binding protein, *torsin* that is expressed most intensely in the dopaminergic neurons of the substantia nigra and striatum, causing alterations in dopaminergic transmission. This may explain the partial responsiveness to levodopa in patients with *DYT1* dystonia.

Finally, this patient did not have any rigidity or bradykinesia, necessary for diagnosis of PD. According to United Kingdom Brain Bank criteria, bradykinesia, is an obligatory feature of PD.¹¹ Strict application of these criteria could have prevented the misdiagnosis.⁴

Conclusion

The diagnosis of dystonia is primarily clinical, and heavily depends on the physician's awareness of the condition and recognition of subtle clinical signs. The incidence of dystonia in VA patients is expected to be lower because many types of dystonia present in childhood, and therefore, patients usually cannot be qualified for military service. Potentially that can further decrease awareness of VA physicians of this condition. Due to clinical heterogeneity and overlapping features with other disorders, dystonia is significantly under-recognized and frequently misdiagnosed.^{2, 7} Our case demonstrates that tremor may be a predominant feature of dystonia and can be confused with ET or PD. However, careful history taking and observation of handwriting may reveal dystonia, resulting in the correct diagnosis. Misdiagnosis of dystonia for PD has significant social, prognostic and therapeutic implications, and financial. It is especially true in VA where PD might be considered a service-connected condition for certain patients. Our case illustrates typical challenges in the recognition and diagnosis of dystonia, and serves to increase clinicians' awareness of this disabling, but sometimes, treatable, condition.

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Advanced Care Planning

Advanced care planning (ACP) is a portion of Palliative Care (PC) in which discussion of desires about future medical care and end of life decisions should be communicated by the patient and their family to the health care providers.¹ It is a specific plan of care that should include at a minimum:

- Establishing a living will and/or power of attorney
- Preferences of care about specific symptoms that may occur such as if you experience psychiatric, physical and cognitive complications which may include dementia or depression, sleep disruption, pain and discomfort or difficulty swallowing and speaking²
- Appointing someone to speak for you when you are no longer able to express your desires of care and determining who will communicate your personal preferences and advanced decision to refuse care or treatment (end of life decisions)
- Where you want to be at the end of your life, your desired place of death

The plan should be reviewed regularly and documented with an updated version provided to everyone who is involved in ensuring the plan is implemented as you desire. ACP has proven to decrease anxiety and stress of persons with PD and their families, decrease in use of life sustaining interventions and increased use of hospice which can aid in providing dignity during death.¹

Coping Strategies for Family Members

- Set jointly agreed upon realistic goals with the person with PD and the PC team with the flexibility to adjust the goals as needed
- Pursue periods of rest by utilizing respite care for time to care for yourself and for emergency needs such as if the family caregiver is hospitalized

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Serving Veterans with Parkinson's Disease Through Telehealth Technology

Virginia Janovsky, MN,MS,RN-BC; Miriam Hirsch, MS,RN,CCRC; Lynn Klanchar, MSN, RN; Susan Heath, MSN, RN

Veterans with Parkinson's Disease in the Veterans Health Administration System

Approximately 65,000 Veterans with Parkinson's disease (PD) receive care from the Veterans Health Administration (VHA) system. PD is the second most common neurodegenerative disease after Alzheimer's disease.¹ It is more prominent in persons over 65 years of age, and 45% of Veterans are in this age group.² About 41% or 3.3 million Veterans live in rural areas of the country. Veterans who live in rural settings tend to be poorer, have higher disease burdens, and have worse health outcomes than their urban counterparts.^{3,4} Despite greater health care needs, rural Veterans are less likely to access VHA health services or have alternative health coverage.^{2,5} The burden of travel to VHA facilities, compromised health and/or limited financial resources may be additional barriers to health care for older Veterans.

The Cost of Parkinson's Disease

PD typically involves a progressive deterioration in function over a 10 to 25 year period. The associated economic burden to persons with PD and to society is significant. It is estimated that more than \$25 billion in health care costs and \$25,000 per person with PD is spent per year, including both direct health care costs (for drugs, physician services, and hospitalization) and indirect costs such as lost worker productivity.⁶ People with PD tend to have higher health care expenses and higher utilization of medical care and long-term care than Medicare beneficiaries without PD.⁷

PADRECC Responds to Veterans through Technology

The PADRECCs, (Parkinson's Disease Research, Education, and Clinical Centers), six regional centers within VHA, have implemented supportive approaches to provide clinical care, psychosocial support, information and education, research, national outreach and advocacy to Veterans and their caregivers.

Providing expert clinical care to Veterans with PD can be challenging due to limited expertise in some VHA facilities. Veterans may need to travel long distances to receive the specialty care they need. Telehealth care, specifically Tele-Neurology within VHA, has helped bridge some of the gaps in health care by clinical video telehealth. Tele-Neurology, which includes Movement Disorders/PADRECC, provides an opportunity for consultative clinical care and collaboration with referral site providers, follow-up care,

visits with other providers, and care coordination. The number of encounters has rapidly increased in the past two years with a high degree of Veteran satisfaction. In addition, tele-education support programs have shown effectiveness in supplementing clinical care and offering opportunities to those in remote areas.

Internet technology use is encouraged within VHA so that Veterans can access their health care records and benefit from health information and resources. An example is VHA's **MyHealtheVet** website, designed to provide Veterans access to wellness and personal health information as well as Secure Messaging with their health care providers. Secure Messaging through MyHealtheVet is a web-based message system that allows participating Veterans and VA health care teams to communicate non-urgent, health related information in a private and safe computer environment. It has proven to be helpful in allowing an alternative communication means to the telephone that is convenient and flexible. In addition, PADRECC staff have also used the internet as a vehicle for educating the public and community. For example, an overview of PD, treatment, and caregiver resources is sponsored on the website of Family Caregiver Alliance, a national center on caregiving.⁸ The **National PADRECC website** at www.parkinsons.va.gov is designed to be Veteran-focused and friendly. Many helpful resources can be found under the major section "For Veterans and Families."

Support groups are also an important resource for Veterans with PD and their caregivers. Traditionally, support groups meet in person, however, participation barriers include health challenges, travel or time resources, and travel distance. To address such challenges, the PADRECC instituted a monthly interactive support group by teleconference that is accessible nationwide to Veterans with PD and their caregivers. Smith and Toseland found that telephone support decreased the amount of strain and depression on the adult caregivers.⁹ In a study by Colantonio, et al., caregivers expressed a preference for telephone support over in-person group settings to meet their psychosocial needs.¹⁰ At some of the PADRECCs, video telehealth technology is used at remote community based outpatient clinics. This allows Veterans to join and participate in support group meetings remotely.

Care coordination, an important component of broad quality improvement strategies, is an alternative approach to health care in

Telehealth (continued from page 10)

which one main point of contact, the care coordinator, helps the Veteran navigate among multiple healthcare providers and systems, manage chronic conditions and avoid preventable emergency visits. The care coordinator identifies the Veteran's strengths and health care issues and aims for the most appropriate treatment while ensuring gaps in care or duplications of care do not inadvertently occur. A Veteran with PD may benefit from care coordination, improving the quality of care as well as patient satisfaction. Care coordination can be administered by telephone and also by telehealth technology.

Currently, a comprehensive care management research intervention, Care Coordination for Health Promotion and Activities in Parkinson's Disease, is being implemented in VISN 22. Nurse specialists conduct structured assessments and proactively identify problems and unmet needs. Identified issues trigger protocols that will be coordinated with the goal of delivering evidence-based, PD treatment guidelines in concert with Veterans' priorities. The primary study outcome is adherence to evidence-based practice guidelines that encompass both motor and non-motor manifestations of PD; secondary outcomes are Veteran self-efficacy, health-related quality of life, and perceptions of PD care quality.

Measures of Success

The success of telehealth information technology can be evaluated by using such measures as:

Veteran-Centered

- Increased time effectiveness of Veteran, caregiver and provider
- Improved collaborative efforts with PADRECC personnel and/or other health providers
- Increased interaction between visits to improve management of PD
- Increased Veteran and caregiver satisfaction

Processes and Outcomes

- Increased provider and staff productivity
- Improved access to care including the rural areas and Veterans with varying socioeconomic needs
- Reduced travel cost for the VA and its related logistics for the Veteran and caregiver
- Reduced health care costs, preventable emergency room and hospital admissions
- Increased engagement by the Veteran and caregiver

- Improved clinical health indicators and quality of life
- Improved self-management by enhancing compliance, which in turn will improve quality of life
- Improved patient-reported and care process indicators
- Improved staff and provider satisfaction

Many Veterans with PD and their caregivers face multiple challenges in accessing health care. The PADRECC's use of telehealth technology has helped bridge the gap in providing expert clinical care and support services to Veterans with PD and related disorders.

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Check out the PADRECC

Education Materials!

"My Parkinson's Story" was produced in conjunction with the Veterans Health Administration Employee Education System. These films provide information about common concerns related to PD. The 14 segments explore specific issues from the perspective of the patient, his or her family and the health care team. Each segment is approximately 8 minutes long. Formats include: DVD, online at www.parkinsons.va.gov, and now on YouTube http://www.youtube.com/playlist?list=PL3AQ_JVoBEyxd5tkfQG-S3p_SDYBFU6c

Restless Leg Syndrome Relief

Lisa Cebrun, BSN, RN, Graduate Student Prairie View A&M University, College of Nursing

Restless Leg Syndrome (RLS) is describes as the periodic need to move your legs in an attempt to relieve unpleasant or uncomfortable sensations. About 15% of the population has symptoms of RLS. Persons with Parkinson's disease may also experience RLS.

What are the signs and symptoms of RLS?

Symptoms can range from mild to severe:

- Overwhelming urge to moves your legs
- Sensations of tingling, jittery, a “creepy crawly” feeling in the legs
- Feelings of itching or pulling in the legs
- A “fizzy soda” running through the veins
- Feeling are more intense with sitting or at bedtime
- Symptoms are relieved by walking or moving your legs



Alternative treatments to try:

- Yoga
- Acupuncture
- Traction Straight Leg Exercises
- Massages
- Aerobic exercise and walking
- Sleeping with a pillow between your legs
- Wearing compression stockings
- Applying cold or hot packs to legs 10 minutes several times a day
- Meditation

Lifestyle changes that may offer some relief:

- Taking hot baths
- Limit caffeine
- Avoid alcohol

2013 Report from Southeast/Richmond PADRECC

Lynn Klanchar, RN, MS, Associate Director of Education, PADRECC Southeast

The PADRECC at Hunter Holmes McGuire Veterans Affairs Medical Center (VAMC) in Richmond, Virginia is making a difference for Veterans and their families with Parkinson's Disease (PD) and other movement disorders. Serving the Southeast region of the United States including VISNs 5, 6, 7, 8 and 9, we provide state-of-the-art clinical and surgical care for Veterans with movement disorders, along with research, education, and community outreach.

Clinical News

Integrated Neurology Center of Excellence Pilot Project: In FY2013, Southeast PADRECC began participating in this national Veterans Healthcare Administration (VHA) initiative. The project will continue through FY2014 with the goal of increasing Clinical Video Telehealth (CVT) in specialty care services. CVT in Richmond has been successful at bringing quality care to Veterans at distant and rural Southeast region VAMCs and Community Based Outpatient Clinics (CBOCs) and minimizing the burden of travel to Richmond.

Deep Brain Stimulation (DBS) surgery at the Richmond PADRECC and Virginia Commonwealth University (VCU) uses the frameless method. This disposable guidance device replaces the traditional heavy frame used in DBS and enables greater patient comfort and participation during surgery. Dr. Kathryn Holloway, Director of PADRECC Neurosurgical Services helped develop the frameless device and also incorporates an intraoperative scanner, the *O-arm*, into the procedure. She recently worked with Medtronic, Inc., on a film project to train more neurosurgeons in these newer techniques.

Research News

Eye Movements A large study is researching specific eye movements in various movement disorders. Preliminary results suggest the ability to accurately differentiate typical movement disorders. "Pervasive Ocular Tremor in Patients with Parkinson's Disease" (Gitchel G, Baron M) was published in the *Archives of Neurology* in August 2012. The research garnered media interest and will be featured in an upcoming issue of *Movement Disorders*.

Repetitive Transcranial Magnetic Stimulation (rTMS) This research is examining the effectiveness of rTMS on speech in people with PD. TMS uses strong magnets to stimulate brain cells. Dr. Kathryn Holloway leads the research team that includes a speech pathologist.

O-arm Accuracy This research determined **O-arm accuracy**, specifically how reliable and accurate the *O-arm* portable, computerized tomography (CT) scanner images were compared to traditional CT images. Study results found efficient, accurate registration and assessment of DBS lead location before the conclusion of surgery. "A quantitative assessment of the accuracy and reliability of O-arm images for deep brain stimulation surgery" (Holloway K) was published in *Operative Neurosurgery* in March 2013.

Education News

Parkinson's Education via Telehealth – each month, a one hour education session on a topic related to PD is now broadcast to CBOCs in Charlottesville, Fredericksburg and Emporia using Telehealth technology. This education is a component of the PADRECC Education & Support Group meeting held monthly in Richmond at McGuire VAMC.

Dr. Mark Baron, Southeast PADRECC Director along with Dr. Steven Schreiber from VA Long Beach Parkinson's Consortium Center, presented "Tele-Provider Hot Topics and Best Practices for Tele-Neurology". This monthly series, presented by VHA Telehealth Services and the Employee Education System demonstrates successful Telehealth clinical models in specialty care.

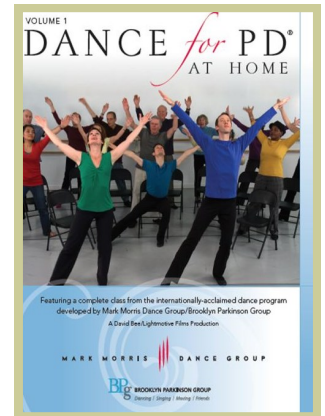
PADRECC Southeast Partnerships with other Parkinson's organizations or those with similar interests continues to grow. An annual PD Community Education Day is sponsored by PADRECC, the local Richmond Metro Chapter of American Parkinson Disease Association (APDA), and the University of Virginia. PADRECC and VCU Parkinson's disease and Movement Disorders Center collaborate to capitalize on shared resources, subject matter experts, and collective creativity. We continue to identify gaps in services and are jointly able to offer more education programs to the movement disorder community. In 2013, PADRECC Southeast and VCU connected with organizations such as Central Virginia Chapter of National Multiple Sclerosis Society, the Richmond Chapter of the International Essential Tremor Foundation, and the American Red Cross. Together we presented a Family Caregiving course in March, an Essential Tremor conference in April, and Support Group Leader Training in May. The Annual PD Community Education Day is slated for October 12, 2013.

New Resource Review

Lynn Klanchar, RN, MS, PADRECC Southeast

The Dance for PD® program has released a much anticipated At Home DVD. For individuals that want to supplement their dancing at home, or for those who don't have a class in their area, this DVD will give them something close to the joyful experience of being in a live class with inspirational and motivating music. The DVD is over 2 hours long with enough material and options ranging from practice classes that will challenge the beginner, to the expedited "through class" that may appeal to an experienced student. Movements were specially designed for people with Parkinson's and can be done seated or standing. The dance phrases draw from tap, ballet, jazz, modern dance and improvisation.

This expertly produced resource is in keeping with the high quality of classes, training, and services offered by Dance for PD® which was developed through a collaboration of Mark Morris Dance Group and Brooklyn Parkinson Group in New York over twelve years ago. The Dance for PD® program is built on one fundamental premise that professionally-trained dances are movement experts whose knowledge is useful to persons with PD. The DVD can be ordered through www.danceforparkinsons.org.



About the PADRECC Logo

Our logo was developed by Eugene C. Lai, MD, PhD, who at the time was the Director of the Houston PADRECC. This logo conveys a visual image of a patient constrained by Parkinson's disease moving from slowness, stiffness, and low spirits, to agility, balance, and joy!

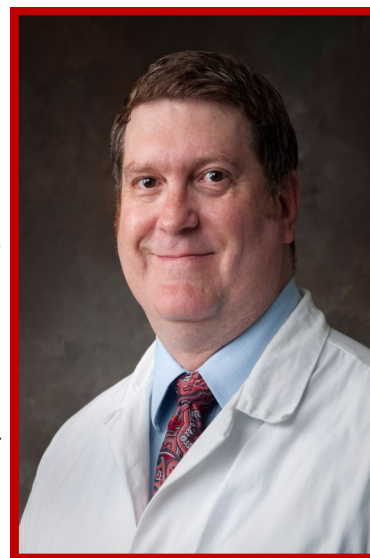
Parkinson's Disease Research, Education, and Clinical Centers are part of the nationwide Network of Care for Veterans with movement disorders.

Houston PADRECC

We welcome Dr. Jackson to the Houston PADRECC!

Dr. George Jackson, is Houston PADRECC's new Associate Director of Research.

Dr. Jackson received the baccalaureate and master's degrees at the University of Texas at Austin and the M.D and Ph.D. degrees from the University of Texas Medical Branch (UTMB) at Galveston. He completed an internship in medicine and residency in neurology at the University of California, Los Angeles and a fellowship in movement disorders with Dr. Jeff Bronstein (now director of the Southwest PADRECC) at UCLA along with research training in neurogenetics at UCLA. Dr. Jackson was faculty in the Department of Neurology and the Semel Institute for Neuroscience and Human Behavior at UCLA until 2008. From 2009-2013 he was professor and held the John Sealy Chair for Parkinson's Disease at UTMB, where he was Director of the George P. & Cynthia Woods Mitchell Center for Neurodegenerative Diseases. He was recently recruited as the Associate Director for Research in the Houston PADRECC at the Michael E. DeBakey VA Medical Center and the Department of Neurology at Baylor College of Medicine.



We look forward to your leadership in PD research.

Congratulations Dr. Pamela Wilson



The American Association of Nurse Practitioners is the largest national organization of nurse practitioners of all specialties in the United States.

As a Fellow of the AANP, Dr. Willson was inducted as a nurse practitioner (NP) leader who has made outstanding contributions to NP education, policy, clinical practice or research, and developing NP leaders of the future. She is an adjunct professor at Prairie View A&M University College of Nursing where she teaches in the Family Nurse Practitioner Program. She is a Co-Investigator for a Baylor College of Medicine Interprofessional Geriatric Consortium 5 million dollar grant to increase NP and Resident geriatric clinical knowledge and skills. At the Michael E. DeBakey VA Medical Center she is the Advance Practice Registered Nurse (APRN) Council Chair and has led the development and implementation of their new Scope of Practice.

Pamela Willson, PhD, RN, FNP-BC, CNE, FAANP, Associate Director of Education for Houston PADRECC, has been recognized as a Fellow of the American Association of Nurse Practitioners.

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